

**Department of Health and Human Service  
Interagency Autism Coordinating Committee  
Meeting Highlights  
November 22, 2002  
National Institute of Health  
Bethesda, Maryland**

*IACC Members in attendance:* Tom Insel (Chair); Ann Wagner (Executive Secretary); Audrey Penn; Duane Alexander; James Battey; Kenneth Olden (represented by Cindy Lawler); Jon Shestack; Lee Grossman; Lucille Zeph; Barry Gordon; Elizabeth Duke (represented by Merle McPherson); José Cordero; Robert Pasternack (represented by Gail Houle); Lester Crawford (represented by Kathy Carbone); Sybil Goldman

Member agencies not represented: Administration on Children and Families (ACF); Agency for Toxic Substances and Disease Registry; Centers for Medicare and Medicaid Services

**Introductions and Overview**

*Dr. Thomas Insel, Director of the National Institute of Mental Health (NIMH) and Chair of the Interagency Autism Coordinating Committee (IACC) called the meeting to order. The minutes from the May 24, 2002 meeting were unanimously approved without modification.*

**Updates on Centers' Activities**

**Collaborative Programs of Excellence in Autism (CPEA)**

*Presented by Duane Alexander, M.D., Director, National Institute of Child Health and Human Development*

Dr. Alexander gave some history of the CPEA centers, which started their funding in 1997 and include 10 sites around the country. He reported that since the last IACC meeting, funding for the continuation of the network had been awarded, initiating the second phase of the network. Nine of the 10 centers were given continuation of funding for the next 5 years, with the 10<sup>th</sup> center resubmitting their application for further funding. The network was converted from program projects to cooperative agreements. Activities of the network include genetic studies, work on a common measures protocol, and a secretin study.

*Discussion:*

A question was raised concerning whether the CPEA meeting in May will be open to the public. The response was that typically much of the meeting, one and a half or two days, is open to the public. A question was also raised about increases in funding, and Dr. Alexander indicated that there are built-in increases in the centers' budgets.

**Studies to Advance Autism Research and Treatment (STAART)**

*Presented by Deborah Hirtz, M.D., National Institute of Neurological Disorders and Stroke (NINDS)*

Dr. Hirtz reiterated the STAART Centers program goal of establishing a network of at least 5 Centers of Autism Research Excellence as stipulated by the Children's Health Act of 2000. The participating NIH institutes are NIMH (lead institute), NICHD, NINDS, NIDCD, and NIEHS. The timeline of the STAART grants was discussed, beginning with the fact that two centers are currently funded, one at Yale University and one at University of North Carolina, Chapel Hill. Round 2 applications are currently under review, and will be awarded in FY 2003. \$12 million per year is expected to fund the program, including center grants, a data coordination center, and collaborative studies among the centers.

*Discussion:*

Questions were raised concerning the focus of research at the STAART centers, compared to the CPEA centers. Dr. Hirtz confirmed that the STAART research portfolio will have instances of overlap with projects represented in the CPEA program, although the STAART grants are required to include treatment and clinical components. Mr. Grossman asked how advocacy groups can help to get more investigators to enter the field of autism research. Dr. Battey mentioned that training young researchers is essential. A discussion followed regarding ways to enhance such training of new investigators. The topic of volunteers for research participation was brought up, and reasons why parents may not be participating were mentioned. The idea of data sharing between the CPEAs and STAART was brought up, and Dr. Insel indicated that a discussion about data sharing is in the spirit of what the IACC was intended to do.

Dr. Insel also mentioned promising instances of senior biologists entering the field of autism research, with the STAART centers having a role in this development. Ms. McPherson brought up the complex service issues related to getting families involved in research.

**Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE)**

*Presented by Jose Cordero, M.D., M.P.H., Centers for Disease Control and Prevention (CDC)*

Dr. Cordero presented updated data on surveillance and epidemiologic studies currently underway in several states. These studies will answer questions related to co-existing disorders as well as whether autism is more common in some groups than others, and whether or not there have been changes over time in the diagnosis of autism. The Autism and Developmental Disabilities Monitoring Network (ADDM) was described, as was working group on questionnaires and medical records abstracting. A case control study that is under development was discussed, as was a large collaborative study with Denmark. Findings from recently published vaccine studies were discussed, including the Danish study which found similar rates of autism in MMR-vaccinated and non-vaccinated cohorts. Dr. Cordero also reported that The Autism Information Center sponsored by the CDC is currently available on the web at:

<http://www.cdc.gov/ncbddd/dd/ddautism.htm>

*Discussion:* A question was raised concerning the Danish vaccine study, and a discussion ensued concerning the specific preservatives used in that study.

### **Scientific Reports from the CPEA Centers**

*Introduction by Lisa Freund, Ph.D., National Institute of Child Health and Human Development*

Dr. Freund introduced Dr. Helen Tager-Flusberg, from Boston University.

*Presentation by Helen Tager-Flusberg:*

Dr. Tager-Flusberg presented results from certain projects within her CPEA grant. She discussed her research as breaking up autism into components based on characteristics (e.g., language) rather than subgroups. Within the area of language, she described the breakdown of difficulties into linguistics and pragmatics, with her current research focused on linguistics. Within the subtype of verbal children with autism, children with normal language were differentiated from children with borderline or impaired language. Children with autism as well as children with Specific Language Impairment (SLI) have deficits in non-word repetition and deficits in grammatical word endings, so children with SLI were used as controls in studies. Similarities were found in atypical brain areas associated with language difficulties for children with SLI and children with autism. A study with adults showed different brain activation patterns were associated with language processing in the autism group. These studies were discussed in relation to linkage analyses, which have shown susceptibility genes for autism and SLI at restricted sites.

Theory of Mind (TOM) studies were also presented, focusing on why some children who exhibit other autism symptoms perform adequately on traditional TOM tasks. A longitudinal study of children aged 4-14 was described, which showed improvement in TOM tasks in children with autism over time, indicating that TOM is impaired but not absent in these children. Language was the factor that predicted improvement in TOM for children with autism. Other language studies relating to TOM were described, including a study of "mind" words and an fMRI study. Face processing studies were also presented in relation to TOM.

*Discussion:*

There was a discussion concerning the line of research Dr. Tager-Flusberg described, and questions were raised concerning sequencing of TOM tasks, animal studies as comparisons for the development of TOM, implications from the facial expressions research for toilet training, and the translation of this research into services.

*Introduction by Lisa Freund, Ph.D., National Institute of Child Health and Human Development*

Dr. Freund introduced Dr. Rodier from University of Rochester.

*Presentation by Dr. Patricia Rodier*

Dr. Rodier presented the results of research implemented through her CPEA funding. She presented previous observations regarding environmental risks associated with

autism, indicating that they have different mechanisms but similar timing that coincides with neural tube closure. She presented four studies. Project I – “Animal models of autism and mechanisms of injury” involved looking at the neuroanatomy of animals exposed to valproic acid during neural tube closure. Project II – “Behaviors discriminating autism in humans and animals” concerned simple behaviors that are deviant in autism, that can be tested in animal models. One behavior tested is the pace of acquisition of conditioned eyeblink in individuals with autism, in comparison to rats exposed to valproic acid in utero. Another behavior tested is disengagement from looking at one screen of flashing lights to another screen. Project III – Genotype-phenotype in autism and behaviorally-related disorders” involved the HOXA1 genotype and expression of the HOXA1 gene after exposure to valproic acid. Studies of the comorbidity of autism and Moebius syndrome were another major theme of this project. Project IV – “Gene-Environment interactions in exposed populations” is a new project looking at candidate genes and determining which genes may interact with exposures known to increase the risk of autism.

*Discussion:*

Questions were raised concerning the specific timing of exposure to toxins, and concerning effects of taking valproic acid during pregnancy.

**Discussion of Research Participant Recruitment:**

*Facilitated by Ann Wagner, Ph.D.; National Institute of Mental Health*

Dr. Wagner opened the discussion concerning research participant recruitment. Difficulty recruiting participants into trials was brought up at the last CPEA meeting, and the investigators wondered if they could be better about communicating to the public regarding research and scientific methods, in order to foster more voluntary recruitment and participation.

Dr. Tager-Flusberg indicated several reasons for success in her program in recruiting participants, including the interest in language aspects of autism, and the time given to the families in providing feedback and written reports.

Mr. Grossman cited parental concerns with regard to participating in research. These included the possibility of feeling like guinea pigs, concerns about being placed in a placebo group, and excessive time and documentation commitment. He described a recommendation from a previous meeting that using personal means of recruiting (i.e. in person or on the phone) may be more successful than other avenues for recruitment.

Mr. Rick Rollins of the Medical Investigation of Neurodevelopmental Disorders (M.I.N.D.) institute stated that he felt partnering with parent organizations in all aspects of research may be beneficial, as he feels that parents want to be involved as well as want something in return for their participation in research projects.

Ms. Goldman reinforced others comments, indicating parents need support, seek information, and want to understand specifics of the research project in which they are involved.

Dr. McPherson stated that she is concerned about under-representation of families who are uninsured.

Dr. Wagner closed the conversation, indicating communication in multiple systems may be helpful, and we can have more discussion regarding partnering with parent organizations.

### **Update on Screening Subcommittee**

*Presentation by Deborah Hirtz, M.D., National Institute on Neurological Disorders, and Stroke and Jose Cordero, M.D., M.P.H., Director, National Center on Birth Defects and Developmental Disabilities*

Dr. Hirtz presented a summary the November 21st meeting of the screening subcommittee of the IACC. The meeting included a presentation summarizing use of the *First Signs* screening kit, as well as a summary of a recent CDC meeting regarding developmental screening for all children. A general discussion of obstacles for developmental screening ensued, which included a conversation regarding screening and diagnostic instruments, methods for informing practitioners and families about the need to screen, issues regarding clinic/office based screenings, referrals beyond initial screening, the need for different approaches for diverse contexts, and possible models from which to work. Recommendations and next steps for the committee to follow were outlined, and included: 1) determining a target audience, 2) determining components for the screening campaign, 3) working on methods for linking families to referrals for service after screening, 4) setting a timeline and 5) outlining methods for evaluation.

Dr. Cordero added that a major change is needed in the practice of pediatricians for screening all disorders.

#### *Discussion:*

A conversation ensued that included comments concerning the possibility of discovering biomarkers, the need to go forward quickly with the screening agenda despite the need for further research and development, and examples of screening programs already in existence. Dr. Insel inquired about the specificity and sensitivity of the instruments currently being used for screening purposes.

### **Report on NRC Recommendations re: Educating Children with Autism and the Center for Training: Autism Spectrum Disorders**

*Presentation by Gail Houle, Ph.D., Office of Special Education Programs; U.S. Department of Education*

Dr. Houle presented “Professional Development in Autism: The PDA Center” by Ilene S. Schwartz, Director of the PDA at University of Washington. Based on recommendations

from the National Academy Press book “Educating Children with Autism,” (which may be found at: <http://www.nimh.nih.gov/autismiacc/educatingchildren.cfm>) the overall goal of the PDA is to conduct training across the country to allow all students with autism spectrum disorders access to high-quality, evidence-based educational services. Guiding principles of the center were outlined, and a strategic plan was presented. The center will provide training to educational teams and parents, review literature on educational models, provide a website clearinghouse, and develop capacity-building activities.

*Discussion:*

Questions were raised concerning coordination of the PDA with non-educational professionals, combining medical aspects of management for children with autism into the program, addressing diversity in children and families with autism, and quality assessment and outcomes measures for teachers of children with autism.

**Update on Services Subcommittee**

*Presentation by Merle McPherson, M.D., Health Resources and Services Administration*  
Dr. McPherson introduced the panel as co-chair of the services subcommittee (with the other co-chair being Sybil Goldman). She discussed the need for bringing services systems together, and raised the question of the need to define the roles and responsibilities of the services subcommittee of the IACC.

**Panel on Services Delivery from the Community’s Perspective**

*Presentation by Lee Grossman, Autism Society of America*

Mr. Grossman introduced and moderated the panel on services delivery from the community’s perspective. He presented statistics regarding rates of autism and costs to society, as well as critical areas to be addressed in order to help the autism community.

*Presentation by Dr. Cathy Pratt, Director, Indiana Resource Center for Autism*

Dr. Pratt presented, “Educating School-age Children Across the Autism Spectrum: Personnel Preparation, Service and Research Needs.” Concerns regarding education of children with autism included training and classroom issues, as well as parent and systems concerns. Recommendations were given, that included: funding of research, focusing on evidence-based practices, training paraprofessionals, increased transition planning for employment, professional development for educators, expanded focus on intervention at the 0-3 age level, and increased family supports.

*Presentation by Myra Alfreds, M.S.W., Comprehensive Community Mental Health Services Program, Westchester, New York*

Ms. Alfreds presented, “Meeting the Needs of Children with Serious Emotional Disturbances and Developmental Disabilities.” She reported on challenges and differences between services for children with mental retardation/developmental disabilities and services for children with mental health issues. A community network for children and families was described, and accomplishments of the Westchester County

mental health services program were reported, including cross-systems planning, collaborative case management services, and curriculum development.

*Presentation by Donna Noyes, Ph.D., New York Department of Health*

Dr. Noyes presented “Clinical Practice Guidelines – Assessment and Intervention for Young Children with Autism.” Early intervention was defined, and models of the Early Intervention Program (EIP) and the Medical Home were described. Service delivery issues for children with autism in the EIP were explored, including the need for funding, the need for improvement in service capacity, and the need for better data on children with autism in the program. The Clinical Practice Guidelines Project was described, with recommendations given regarding guidelines for autism interventions. Other efforts needed to promote quality services to children with autism were explored, and included developing standards and reimbursement rates for paraprofessionals, and training and technical assistance.

*Presentation by Ann Holmes, M.S., CCC Eden Services*

Ms. Holmes described services for adults with autism at the Eden Family of Services. She presented descriptions of Eden services, including group homes, employment programs, and school-based programs. She discussed the gap in services for adults with autism, the high percentage of adults with autism who are institutionalized, challenges of adults with autism living in group homes, and the need to improve the field of human service provision. Entitlement for funding and support for adult services were also discussed.

*Discussion:*

Following the presentations, the speakers summarized their “take home” messages. Dr. Noyes emphasized the pressure for evidence-based interventions, Ms. Holmes focused on the necessity of entitlement for funding, Dr. Pratt pointed out the need for involvement of the insurance and Medicaid sectors, and the need for systems to work together, and Ms. Alfreds commented on the energy in the family movements, pointing out the gray areas with respect to research and categories. She also brought up an increasing trend in medicating children with autism. Dr. Gordon asked if the service providers generally agree on educational recommendations for children with autism, with a response that they do generally agree. Mr. Grossman pointed out that the majority of programs for children with autism are not working. Dr. Zeph commented on the need for more research on services.

## **Scientific Reports on Pharmacotherapy in Autism**

### **Psychopharmacology of Autism Spectrum Disorder**

*Presentation by Kathryn Carbone, M.D., Food and Drug Administration*

Dr. Carbone presented on the current state of psychopharmacology research relating to autism spectrum disorders. She described special issues in psychopharmacology research particular to autism, including the life-long nature of symptoms in autism and the current

lack of knowledge regarding the biological bases of autism. She indicated that psychopharmacologic treatments have improved symptoms such as self-injurious behavior, aggression, hyperactivity and social disturbances. She commented on data used for treatment decisions, which include case reports, case series and prospective studies. Dr. Carbone discussed the FDA's responsibility to determine whether a drug is efficacious and safe for treatment of a specific disorder. She discussed the categorization of positive result quality, and summarized findings on a variety of psychopharmacologic agents previously studied in the autism population.

### **Results from the Risperidone Study and New Directions**

*Presentation by Benedetto Vitiello, M.D., National Institute of Mental Health*

Dr. Vitiello presented recently published findings from a Research Units on Pediatric Psychopharmacology (RUPP) study of risperidone in children with autism. Risperidone was hypothesized to reduce symptoms of impulsive aggression, agitation, and self-injurious behavior in children with autism. The study included a randomized, double-blind, placebo-controlled design. Reported findings supported the hypothesis that risperidone significantly reduced severe behavioral problems, with the side effect of weight gain.

### **Open Session for Public Comment**

#### **Discussion:**

Rick Rollens from the M.I.N.D. Institute welcomed Dr. Tom Insel as the new NIMH director. He also pointed out the need for better subtyping of autism. He also commented on the screening issue in lieu of the need to reduce delays in getting children diagnosed with autism. Lastly, he reported on his conversation with the department of Developmental Services in California regarding increasing numbers of children with autism.

Jamie Ruppman, parent of an adult with autism, and director of governmental relations for TASH spoke about an upcoming meeting of TASH (an international association of people with disabilities), and invited IACC attendees to a meeting concerning barriers to supports and services for adults with autism. She also discussed parents as partners to researchers and practitioners.

Bernice Polinsky, from Long Island, New York, spoke about her role as a co-facilitator of a parent support group for parents of older teens and adults, and she mentioned the high frequency with which she hears of diagnosis of autism occurring during adulthood.

Shari Chase spoke about the need for researchers to consider environmental issues such as heavy metals and pesticides. She also spoke of issues concerning the complexities of obtaining a diagnosis and insurance reimbursement. She recommended the training video *Fat City*.

Ms. Schissel, from Long Island, New York, spoke about the inconsistency of diagnoses made by practitioners and the school system

Dr. Gordon also discussed inconsistencies in diagnosis, between the medical/scientific, educational, insurance, and political/legal levels.

Dr. Vitiello addressed the diagnostic inconsistency issue, pointing out that technical instruments exist to solve disagreements in diagnosis.

Dr. Catherine Rice discussed efforts at the Centers for Disease Control and Prevention (CDC) currently underway to examine surveillance data on the incidence and prevalence of autism. She also pointed out that findings from these studies may help inform the public about children with autism who have not been labeled as such previously.

Mr. Rollins of the M.I.N.D. Institute spoke about the recently released study from the M.I.N.D. institute concerning the diagnostic issue. He highlighted the increase in numbers of children diagnosed with autism in the California Developmental Services system.

### **Strategic Planning for the IACC**

#### **Setting Goals/Agenda for the IACC and Next Steps**

Dr. Insel summarized the meeting, indicating the next meeting will most likely be May 13, 2003. He spoke about the subcommittee work that will occur in the interim, and the fact that the website will be used to provide a record of today's meeting as well as maintain relevant links. He requested input regarding the agenda for the next meeting, as well as suggestions regarding the format of the meeting. He highlighted the need to have people talking across agencies, particularly with regard to the services arena.

**The meeting was adjourned at 5:00 PM**